UNIVERSITY OF ALBERTA

THE EVALUATION OF A SIMPLE EDUCATIONAL INTERVENTION ON THE COMPLETION RATE OF ADVANCE DIRECTIVES

BY

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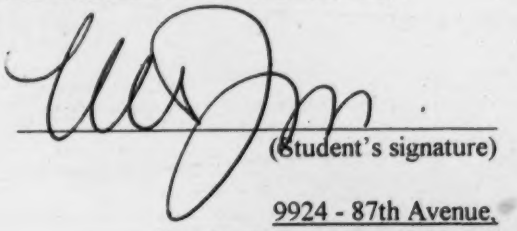

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DEDICATION

This is dedicated to the gentleman who was in excruciating pain due to extensive metastatic cancer with only days to live, who died peacefully one summer afternoon and was forcibly brought back to life through CPR, defibrillation and Advanced Cardiac Life Support medicine. I am so very sorry.

ABSTRACT:

The goal of this study was to assess the potential of advance directive education within the context of a pre-admission clinic. A prospective completely randomised one intervention trial was undertaken in the Pre-admission clinic (PAC) at a large tertiary care institution in western Canada. All patients (18 years and older) who were admitted through PAC, and went home between pre-admission and surgery, comprised the study population. The experimental group (N = 50) received, in the PAC, an educational package which included: an advance directive - (AD) and a brief discussion about advance directives. The control group (N = 50) followed the usual pre-admission procedure which did not include an AD educational package. Post-operatively, the outcomes measured were: completion of a written advance directive and/or a verbal advance directive and the degree or level of satisfaction with the educational package, the timing and milieu of the AD education. The proportion of the experimental and control groups who reported they had written or discussed advance directives was compared. Some subjects in both groups indicated they had written an AD prior to the PAC experience, (12% in the experimental group and 10% in control). The written rate of AD following the intervention was 21.5% in the experimental as compared to 0% in the control. The verbal AD rate following the intervention was 77% in the experimental as opposed to 0% in the control. 75.8% of the experimental group surveyed thought that the PAC time frame was a positive venue for AD discussion. The qualitative data findings confirm this but subjects note that this education does add stress to an already

stressful situation. However, they perceive this time as undoubtedly less stressful than education on admission

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My mother and father always believed in the intelligence of women, I started a Masters because of this. My parents taught me to always search for and embrace ethics and ethical conduct because of this I seek to assist those that desire autonomy.

My sister, my best friend; the backbone of my soul:without whom I could not exist.

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TABLE OF CONTENTS

CHAPTER I: INTRODUCTION	page. 1
PURPOSE.	page. 3
RESEARCH QUESTIONS	page. 3
DEFINITION OF TERMS	page. 3
SIGNIFICANCE OF STUDY	page. 4
CHAPTER II: LITERATURE REVIEW	page. 6
THE IMPORTANCE OF AD RESEARCH.	page. 6
THE PROBLEM WITH ADS.	page. 8
THE AD EDUCATION LITERATURE	page. 9
OUTSTANDING EDUCATIONAL OUTCOMES	page. 10
CHAPTER III: METHODS	page. 14
RESEARCH DESIGN	page. 14
RECRUITMENT OF STUDY SUBJECTS	page. 14
SAMPLE SIZE & POWER CALCULATIONS	page. 15
STUD FLOW CHART	page. 16
DATA COLLECTION PROCEDURES	page. 17
DATA ANALYSIS	page. 20
ETHICAL CONSIDERATIONS	page. 20
CHAPTER IV: FINDINGS	page. 23
TABLE 1	page. 25

CHAPTER V: DISCUSSION page. 30

WRITTEN ADS. page. 30

VERBAL ADS page. 32

PATIENT SATISFACTION page. 34

REACTION TO THE AD TOOL page. 37

IS PAC A TEACHABLE MOMENT? page. 39

LIMITATIONS OF THE STUDY page. 40

GENERAL RECOMMENDATIONS FOR NURSING page. 41

RECOMMENDATIONS FOR FURTHER RESEARCH page. 42

REFERENCE LIST page. 44

APPENDIX I page. 53

APPENDIX II page. 55

APPENDIX III page. 57

APPENDIX IV page. 59

APPENDIX V page. 61

APPENDIX VI page. 63

CHAPTER 1

Introduction

There are numerous situations in which suffering and the dying process are aggravated by modern health care (Dossetor, 1992). For example, patients with excruciating, intractable cancer pain, who have no hope of relief or recovery may be resuscitated back to 'life' with cardiopulmonary resuscitation (CPR). Those who have an unwitnessed arrest are often resuscitated into a persistent vegetative state[1] and then are maintained in this hopeless 'no man's land' (Bioethics Centre and the University of Alberta Hospitals, 1994) and may even be treated with drugs when they contract a life-threatening illness (Loewy, 1994). Competent Canadians have the legal right to refuse treatment. "The right of a person to control his or her own body is a concept that has long been recognised in common law. The tort of battery has traditionally protected the interest in bodily security from unwanted physical interference" (Kluge, 1993, p.317). This includes refusal of any technology that they perceive not to be beneficial, even that which would maintain their life.

But what of the incompetent person? What of the person who is not judged to be of 'sound mind'? Those with a dementia due to Alzheimer's disease or those with an inability to represent themselves because of coma, persistent vegetative state, unconsciousness, or stroke are judged to be incompetent, and so lose their right to self-determination (Janofsky, 1995; Janofsky, McCarthy & Folstein, 1992; Krynski, Tymchuk, & Ouslander, 1994; Silberfeld, Nash & Singer, 1993). Thus, suffering and

1. The persistent incognitive vegetative state is just one extreme form of ischemic brain damage.

the dying process may be prolonged in these humans because only a court appointed, legal guardian has the authority to stop their treatment. The doctors and the courts cannot know the competent wishes of the incompetent patient without an advance directive and so must legally assume a 'pro-life' stance, when the condition is not deemed 'futile" , keeping these individuals 'alive' 'at all cost' (Catholic Health Association of the United States, 1990).

A mechanism to give all human beings the ability to maintain control of their lives after they have become incompetent has been evolving since the Patients' Rights Movement of the 1960's. This mechanism is called 'advance directives' (AD), 'living wills', or personal directives[1]. These names refer to written documents that are formulated by a competent person for the possible contingency of incompetence. It is a list of the individual's health care wishes as well as the name of a personal representative who will speak for them if they cannot or are unable to do so. Dossetor states that "it is important to realise that these advance directives are the only defence the average person has against the inappropriate application of high-tech medicine" (1992, p. 3).

Despite the perceived importance of ADs, the effective application of these documents has been highly problematic. As Singer has stated, "people like living wills, but they don't write them" (Singer, personal communication, 1995). Implementation strategies need to be developed that will assist those individuals who want a living will.

1. 'Living will' is the original term given to phenomena of written end-of-life decision; these do not include a proxy. The term 'advance directive' represents the modern North American document which combines both proxy and client preferences. 'Person Directive' is the term given to advance directives in Alberta.

Many educational interventions have been attempted but they are either too costly or too ineffective. Highly intensive interventions do induce persons to complete ADs, but these would be too expensive on a wide scale intervention and simple education such as pamphlets do not induce a clinically significant change in patient behaviour.

Purpose

The purpose of this study was to evaluate the impact of a simple AD educational intervention, in a surgery pre admission clinic, on the rate of written and verbal of advanced directives by adult surgical patients.

Research Questions

The primary question of this study was:

What is the impact of a simple AD educational intervention in a surgery pre admission clinic on the rate of written completion and verbal discussion of advanced directives by adult surgical patients.

Secondary questions were:

1) How do patients respond to AD education in a PAC setting?

-how do they respond to the 'timing' and the milieu?

2) How do patients respond to a scenario and treatment specific AD? (Emanuel, L. 1993)

Definition of Terms

Simple educational intervention: was defined as the handing out of an AD document to research subjects, combined with a short discussion on the topic.

AD: Advance directives are written documents that are formulated by a competent person for the possible contingency of incompetence. It is a list of the individual's health care wishes as well as the name of a personal representative who will speak for them if they cannot or are unable to do so.

Pre-Admission Clinic (PAC): is a hospital unit in which adult patients are prepared to go through surgery by nurses, doctors, technicians and ward clerks anywhere from one day to usually several days but sometimes months prior to their admission to hospital for surgery. These PAC visits may last from one to six hours on average. A nursing and medical history and physical examination are completed. Patients are taught post operative skills and any questions that a patient may have are answered by nurses and doctors. Depending upon the other medical conditions of the patient and the extensiveness of the surgery, patients may undergo various other procedures such as consults from specialists, electrocardiogram documentation, X-ray, ultrasound, or CT scan.

Written AD: was defined as signed, dated and witnessed AD.

Verbal AD: was defined as a verbal expression of an AD to someone who could and would become involved in the event of the patient becoming incompetent.

Significance of the Study

This investigation was important because it attempted to further explain the extraordinary data generated by the Cugliari et al. (1995) trial. This trial achieved a written rate of 36% after the simple intervention of pamphlets and one face to face interaction within in PAC setting. If these findings are reproducible it would help determine the appropriateness of the PAC setting as a venue for AD education. The

best time and method of providing information on AD to people is the key issue in AD education.

CHAPTER II

Review of the Literature

In this literature review, the importance of advance directives are discussed along with the difficulty in their completion. Research in which various educational interventions are attempted in order to increase the completion rate are examined and the point is made that the outcomes of the research are inconclusive except to say that very labour intensive, expensive interventions produce outstanding results and inexpensive educational methods have very poor results.

The Importance of Advance Directives in AD Research?

Increasingly, advance directives are considered to be of major importance: ethically, legally, socially, and practically. Whole books on the subject are starting to emerge (Molloy, 1993; Cantor, 1993) as well as histories, overviews, and explanations (Teno, Hill & O'Connor, 1994).

There is growing general agreement that advance directives are a 'good thing' though not a panacea. Many ethicists concur that patient autonomy and self-determination are foundations upon which moral decisions must be based and these values are enshrined and promoted by the advance directive. As well, modern ethical precepts, such as relational ethics, feminist ethics and distributive justice (Cox & Sachs, 1994; Iris, 1995; Gadow, 1980; Gordon & Singer, 1995) may also be served by the mechanism of the living will.

Legally, it has become increasingly clear that advance directives are needed in order to withhold treatment and to discontinue life support for incompetent persons (Catholic Health Association of the United States, 1990). The Supreme Court of the

United States has stated that a feeding tube for a person in the persistent vegetative state cannot be removed without an advance directive (Cruzan vs. Missouri). Thus, without living wills there are often inadequate mechanisms to allow a brain dead individual to die, however, the legality regarding 'medical futility' does aid with cessation of treatment (Sneiderman,1999). From a health care prespective, advance directives are very important due to the well documented fact that if people are old and sick, CPR frequently resuscitates people only temporarily; almost always this group of people rearrest or never regain competency or quality of life in which they are able to go home; many times this group are revived into a persistent vegetative state. (J.B. Dossetor, personal communication, November 13, 1995; Lazzam & McCans, 1991; Moss, 1989; Von Guten, 1991). CPR and Advance Cardiac Life Support (ACLS) are appropriate when that is the autonomous wish of the patient. However, often patient wishes have not been obtained and thus there is the possibility that the hospital routine of CPR and ACLS are contrary to the philosophy of the client.

Sociologically, there is also need of a formalised documented system to stop treatment because health care has moved from an intimate and rural milieu, where patients and their wishes are known, to an impersonal and urban setting, where persons and their values are unknown (J.B. Dossetor, personal communication, November 13, 1995). Therefore, there is the need of a more impersonal way of knowing the healthcare wishes of the patient. There is need of a document such as an advance directive.

Currently, in Alberta, The Personal Directives Act (1997) has been passed (Alberta Law Reform Institute, 1993). This statute will clarify Canadian advance directive case law (i.e., Malette vs. Shulman) and has legally entrenched the right of self

determination of the incompetent person in Alberta. The problem still arises though on how to facilitate the implementation of ADs by people before they become incompetent.

In general, research has substantiated the fact that people like the idea of advance directives (Kohut & Singer, 1993; Robertson, 1993; Sam & Singer, 1993; Smucker, et al, 1993).

Further, people like to talk about living wills and want to be asked their preferences about life support (Layson, Adelman, Wallach, Pfeifer, Johnston, & McNutt, 1994).

Advance directives are basically then seen as a 'good thing'. They enshrine 'western' society's ethical and moral imperatives. They serve as a legal mechanism to protect the rights of the incompetent person, as well as acting as a practical medical restraint from potentially ineffective or unwanted CPR. Finally, people, as research has shown, want to discuss and decide upon these end of life issues and value the opportunity to express their personal directives.

The Problem with Advance Directives

Despite overwhelming evidence of the benefits of advance directives, people do not write them. Only 12% of Canadians have filled out a living will (Kohut & Singer, 1993). Although there are many barriers mentioned in the execution of these documents, the most cited reason is the lack of knowledge and understanding. People do not know about the existence of advance directives (Kohut & Singer, 1993), their purpose, or the mechanism by which they may be completed (Jacoson, White, Battin, Francis, Green & Kasworm, 1994; Sam & Singer, 1993; Silverman, Fry & Armistead, 1994).

One might imagine that a simple educational intervention could clear up this problem. However, it has proven very difficult to educate people about living wills. Singer states that advance directives are the "educational challenge of the '90's" (Singer, personal communication, 1995).

The Advance Directive Education Literature

One of the greatest current concerns reflected in the advance directive education literature is method of education, specifically, the most effective way to educate people about advance directives. Research has demonstrated that simple educational methods effect little or no change in objective patient outcomes; that is, the rate of completion of person ADs. Short discussions (which typically take place in a doctors' office) and written brochures are enjoyed by the patients; however, these brief educational exchanges do not induce people to write advance directives (Emanuel, L.L., 1993, Sachs, Stocking & Miles, 1992; Singer & Siegler, 1992). Typically, these simple educational interventions have resulted in a 5% (Sachs, Stocking & Miles, 1992) to 25% completed document rate (Richter, Langer, Fawcett, Paine-Andrews, Biehler & Manning, 1995).

This low response rate reinforces what has been learned in other areas of health teaching. Health care education must affect more than cognitive comprehension (Este & Anderson, 1995; Lipkin, 1996; Sachs, Stocking & Miles, 1992). As many studies in smoking and weight loss have demonstrated, simple cognitive change is not sufficient to change behaviour (Estee, 1995). Education that is intended to affect conduct must be much greater than an intellectual sermon. It must be a holistic process

(Faber-Langendoen & Bartels, 1992; Ventres, 1992) and it must address all of the domains of the person including the cognitive, attitudinal, instrumental, planning, and coping human being (Lipkin, 1996). Thus, giving the patient a lot of information about advance directives is not all that is required if the outcome sought is the formulation of a document.

Prochaska (Pearlman, Cole, Patrick, Starks, & Cain, 1995) has proposed an educational model that illustrates a holistic process to change patient behaviour. It is a five stage model which documents patient change from topic introduction, through facilitated and supported discussion, as well as reflection, to a stage in which action is contemplated, validated, and finally updated. The small number of advance directive educational interventions that have successfully effected substantial objective outcomes have based their programs on these types or processes of change (Bartlett, 1991; Colvin & Hammes, 1991; Kellogg & Ramos, 1995; Pearlman et al., 1995). These intervention programs have involved highly trained specialists who teach, encourage, and support their patients through 'a Prochaska like' process that involves numerous meetings and sessions (Godkin & Toth, 1996; Perry, 1995; Thompson, 1991). Furthermore, Tilden, Tolle, Garland and Nelson (1995) report that patients and families find support, clarification, facilitation, and encouragement very helpful in the formulation of advance directives. The Prochaska model of change would seem to be a valuable tool to address the process of advance directive education.

Expensive and Outstanding Educational Outcomes :

There have been a number of complex, time consuming, advance directive educational programs that have had outstanding objective success. Analysing these

programs sheds light onto educational methodologies, and the processes which have induced higher written rates.

Molloy and Guyatt's (1991) educational intervention had an advance directive completion rate of 76% . There seems to be several reasons for this success. A comprehensive educational package was used (Molloy & Guyatt, 1991) and the educational experience unfolded as an individualized process, not unlike that of the Prochaska (Pearlman et al., 1995) or Emanuel et al. (1995) processes. In addition, the education took place within a home for older persons, which has been noted as a successful milieu for advance directive education because these seniors are a captive audience (Kellogg & Ramos, 1995). As well, nurses and social workers were used as facilitators and educators. It has been documented that patients have viewed the AD assistance provided by these professionals very positively (Coate Johnston, Pfeifer & McNutt 1995; Haisfield et al., 1994; Jezewski, 1994).

Another successful study, similar to Molloy et al. (1991), was that of Luptak and Boult (1994). This study utilized a very individualized structure, with written information, discussion, review, and emotional support. The researchers took a significant amount of time with each person (i.e., 60-90 minutes). A 71% success rate was reported, although, the sample size was only 34. The primary practitioner in this instance was a social worker.

A third successful intervention was that by Godkin and Toth (1996) who effected a completion rate of 38%. This study also used the Molloy (1991) package for patient education, as well as an educational process similar to Molloy et al. (1991) and Prochaska (Pearlman et al., 1995). In this research, a nurse specialist was used as the

facilitator/educator rather than in combination with a physician as in Molloy et al. (1991) and the patient population in this study was outpatients rather than nursing home residents.

Schneiderman, Pearlman, Kaplan, Anderson and Rosenberg (1992) studied 204 outpatients with "life threatening illnesses" and a life expectancy of less than five years. Their completion rate was 66%, although this was not the focus of the research. The experimental group were asked and encouraged to join the research. Their participation indicated agreement to fill out an advance directive. In attempting to understand this trial's success, one notes the obvious contributing factors of the patients' very poor prognoses and the physician's insistence upon AD completion which may be viewed by some as coercion.

Thus, time consuming, labour intensive, personalized educational processes can be very effective in inducing a substantial written AD rate. As seen with other health teaching concerns, the health provider must address and allow for a process of change to occur. The Prochaska model allows for the complex changing of the person as they move toward a health care action .

Consequently, one appears to be left with a terrible conundrum. If the only useful educational method requires a huge amount of time and expertise to facilitate, to teach and to support, then what is the cost of advance directive education? If each patient takes 60 to 90 minutes, as was done in the successful studies mentioned above, then what is the financial burden to a society who wishes to offer autonomy to its populace? It becomes imperative to determine if there is a simpler way to educate people effectively about advance directives.

There is one study which used a simple educational program and demonstrated a substantial outcome. Cugliari, Miller, and Sobal (1995) gave 419 pre-operative patients who were 18 and over, a pamphlet and an advance directive document when they visited a pre-admission clinic (PAC) for their preoperative 'work-up'. Forty percent of the study population wrote an advance directive. This was compared to a control group, in another hospital, who received the same information, in the admitting department, on the day of admission to their surgery. Only 4% of the control group wrote an advance directive; however it is not clear that this group was comparable because it was recruited from an entirely different population at another hospital, and the timing of the intervention was not similar.

Summary of the Literature Review

Advance directive educational programs have been shown to be most effective when they are personalized in-depth processes. Simple, inexpensive educational methods have had poor results, except for the study by Cugliari et al. (1995) which had a 40% advance directive completion rate. This study used the pre-admission time frame before surgery to influence an effective process of change. However, this research has weak external validity due to different experimental and control populations. Therefore, this potentially very important research needs to be re-enacted on one population in order that its successful outcome be substantiated

CHAPTER III

Methods

Research Design.

A prospective completely randomized one intervention trial was used in this study to address the research objectives. Subjects were chosen for this study using strict inclusion criteria (see below) and the recruitment of subjects used randomized sampling techniques.

Recruitment of Study Subjects

All adult surgical patients who attended a pre-admission clinic prior to elective surgery were the target population for this study. Subjects were selected for inclusion if they met the following criteria: competent adults (18 years or older), preparing to have surgery, and going home between pre-admission and surgery.

Subjects were excluded if they were day surgery patients (having a 'small' procedure done), day of surgery PAC patients, that is those admitted through PAC in the morning before their surgery, medical patients not slated for surgery, obstetrical cases, people from out of town who are going to surgery immediately, paediatric patients, and patients who were deemed incompetent by the PAC staff at the time of pre-admission.

Patients, who met the inclusion criteria were randomly recruited into either the experimental group or control group in the PAC clinic . The start date for recruitment was picked randomly using weeks of the month picked from a hat and day of the week

picked from a hat. It was decided whether control or experimental subjects would start first in this manner.

Group recruitment alternated on a daily basis. This was done in order to ensure group comparability with respect to potential extraneous variables such as differences in surgery rotation, types of surgery, levels of patient acuity, and prognosis. Further, if there had been any local media or impact with respect to this topic, then the two groups would have been affected equally[1]. For example, if all of the controls were questioned pre-media blitz, and all of the experimental group were interviewed post blitz, then the media would represent a serious confounder.

Patients refusing to participate were asked if they would mind sharing their reasons for non-participation and these were noted. If they refused, their reasons remained unknown, thus, forming a limitation of the study.

Sample Size and Power Calculations.

With 50 subjects per group (i.e., experimental and control groups), using a one-sided test at alpha =0.05, there is approximately 99% power to detect a response rate difference of 36%. This sample size and resulting study power was considered more than adequate to address the study's research questions. The actual size and power calculations for this study can be found in Appendix 1.

1. It was expected that the provincial government might introduce its Personal Directives Act during the period of data collection and this announcement did occur as anticipated.

Study Flow Chart:

Two-group between-subjects after-only design (Christensen, 1991, p. 282):

Sample of Subjects = N = 100

PAC surgical population = competent, adults, preparing to have surgery and who will go home between pre-admission and surgery
randomly assigned to

experimental group (N=50)		control group (N=50)
treatment = AD education		no treatment = usual PAC
completion rate E	vs	completion rate C

Compare proportions with a 'z' test

Intervention: The intervention was modelled following the Prochaska model of change.

1. Pre contemplation: In the pre admission unit, the patient was introduced to advance directives with a 'living will' package: an information booklet and a useable document (High, 1993). The person and their family were given a brief introduction (five to ten minutes) and the patient was encouraged to share and discuss this material with their loved ones (High, 1993). Further, they were directed to call the researcher should they have any questions or concerns (High, 1993).

2. Contemplation: Advance directive contemplation could have happened within the context of the patients' own home, environment, and family. Thoughts and discussions about advance directives were not primarily with a health care professional, but rather with those that the patient most loves and trusts; within the family milieu of their home.

3. Preparation: Discussion and writing (the most cited advance directive barrier (Sachs, Stocking & Miles, 1992)) of the advance directive may have been facilitated by the up and coming surgery, which acted as a type of life crisis. The surgery can act as a change impetus.

4. Action: Action may in theory be facilitated by the window of time after education, before surgery and by the facilitation of the health care professional as a potential resource.

5. Maintenance: On admission, the patient was asked about their advance directives and their specific wishes. This may have served as a review for the person.

Data Collection Procedures

Patients waiting for PAC tests, who met the study inclusion criteria, were approached by the researcher and asked if they would speak to her (see appendix II). During this interaction, the researcher demonstrated a nursing persona of warmth, compassion, and professionalism. Once permission was given by the patient the AD intervention commenced. The intervention consisted of two parts;

1) A brief discussion by the researcher. This discussion as outlined in Appendix I, briefly describes the concept of the living will; shows the person an example of an uncompleted advance directive, encourages them to discuss this with their family and to call the researcher if questions arise. The patient is not encouraged to fill out the AD. There is no coercion. The person is told that the AD may be used if they decide that that is what they want.

2) A 'real' advance directive, The Medical Directive developed by Emanuel and Emanuel, 1995, was given to each person. This medical directive outlines health care options with respect to certain illness scenarios and has a proxy nomination section as well as places for signatures that legalize this document.

The Medical Directive has undergone extensive testing and revision. It has face and content validity; only 1% of choices were clinically illogical (Emanuel, L.L., 1995).

Item response analysis indicates that the treatment-specific responses correspond to selections for general goals of care sufficiently to affirm construct validity. The Medical Directive has shown good predictive validity. With respect to test-retest reliability, patient's choices were as stable as those made by physician's.

Post operatively, the outcome data were collected at the bedside by the researcher or research assistant. Neither the researcher or the assistant were blinded to the research objectives or group assignment. However, the experimental subject was not completely aware of the purpose of the study. So as not to influence, what was emphasized was that the purpose of the research was to assess the PAC time frame for AD education. The researcher made clear to subjects that the decision to write an AD is purely at their discretion. The scripts in Appendix II were followed and the research assistant maintained the same attitude as the PAC researcher. The control group received the normal PAC procedures. They were approached post-operatively and were questioned according to the script in Appendix III.

Post-operatively, both groups were asked if they had: (1) written an AD, or (2) given a verbal AD. In addition, the experimental group was asked about the experience of learning about ADs in the PAC milieu (see Appendix I). These three outcomes were addressed because scholars differ on the outcomes that they value. Some believe that a *written advance directive* is the only valid outcome (P.A. Singer, personal communication, September 12, 1995). Other researchers hold that *patient satisfaction* is the outcome of choice (P.A. Singer, person communication, September 12, 1995), because it reflects the patient's belief that they have been well served by the health care profession. Researchers who hold relational ethics as paramount, believe that *discussion*

is the outcome of choice (Bergum, personal discussion, 1995; Dossetor, personal communication, April, 1997; Haas, Weissman, Clery, Goldberg, Gatsonis, Seage, Fowler, Massagli, Makadon & Epstein, 1993). Discussion represents a very meaningful outcome because it may enhance the family's cohesion with regard to treatment choices. It may also maintain the patient's autonomy at the time of incompetence because many physicians will defer to a united family who seem to speak on behalf of the patient (Dossetor, personal communication, 1995).

Research has shown a higher outcome of ADs when verbal reports of written documents have been used as opposed to written AD s attached to the patient chart (Richter, Langer, Fawcett, Paine-Andrews, Biehler & Manning, 1995; Hare & Nelson, 1991; Sach, Stocking & Miles, 1992). These authors' research demonstrate that a charted living will was, perhaps too much to ask. For some persons it was too daunting to formulate an advance directive of which one is so certain that one is able to write it in ink: to take it to one's doctor who will write it indelibly within 'the chart'. In this study therefore rather than insisting on documented proof, the patients were asked verbally if they have a written directive. Because subjects may not have understood the question, probing questions were asked such as the whereabouts of the document, and the persons with knowledge of it, as well as details as to the content (see Appendix I).

Questions were asked as to whether the PAC time frame was a good milieu to receive the information, whether the pamphlet was written clearly and at a level the person could understand, and if any additional information should have been included that would assist them in completing an AD. Demographic data were obtained to

determine group comparability on extraneous variables (i.e., the kind of the surgery) that could be used to explain significant study results.

Data Analysis

Baseline comparability between the experimental and control groups was assessed to determine if randomization had controlled for potential extraneous variables that may have influenced and explained a significant study outcome (dependent variable), rather than the intervention. The factors that were assessed are outlined in Appendix IV.

In order to evaluate the impact of the intervention on the rate of completion of ADs, differences in completion rate between the experimental and control group were assessed by means of a test of proportions (one-sided, z-test) at alpha =0.05.

Ethical Considerations:

One of the greatest threats to the autonomy of the person writing the advance directive is coercion (J. B. Dossetor, personal communication, November 19, 1995). Coercion exists as a negative raison d'etre for the written directive. Subtle forms of this influence may creep into any stage of the formulation process. Obviously, this detracts from the ethics of these documents. The formal process of consent may act as a coercive element. In the Schneiderman, Pearlman, Kaplan, Anderson and Rosenberg (1992) study, almost all of the subjects who formally consented to the advance directive study completed a living will. Therefore, the process of formal consent seems counter productive in research which studies written outcome.

On the other hand, to withhold or conceal intent of research is by definition deception. This is of course unethical. How then to find an ethical path between these

two phenomena. Is there some line which can be walked upon that will not fall into either of these unethical conundrums.

Perhaps the 'right thing' is a middle path that tacks between the two ethics and relies upon a semi-blinded consent as depicted in Appendix IV. This study then has attempted to minimize coercion by refraining from a formal enrolment process which dictates that the purpose is to evaluate the written and verbal completion rate and minimize deception and maximize the voluntariness of the subjects, by obtaining formal consent to educate and to evaluate the timing of the education.

This consent at the teaching stage seems ethically appropriate because of the nature of the intervention. The intervention involves the passing out of basic advance directive information in an informal way. The education literature is vetted and promoted by the hospital in which it took place (in fact their own brochures on the subject are easily available to the patients) and by the provincial government (who have just passed an AD law called the Personal Directives Act). Thus the dissemination of the information is not extraordinary in its substance and can be seen as a further educational service given to the patient preoperatively.

Patient anonymity was maintained by assigning a number to each of the subjects and these were used on all accessible material for data coding and entry. Data obtained on timing, clarity, noncompletion/nonparticipation were pooled in reports on this study. The names and code numbers of subjects were maintained in a locked filing cabinet and will be destroyed on completion of the study. Data will be maintained for a period of seven years and then destroyed. Subjects were encouraged to call the investigator or her supervisor with any questions or concerns that they might have.

Permission for the research was obtained from the physician and nurse in charge of the PAC. As well a negative consent (Appendix V) was obtained from surgeons whose patients are seen in PAC. Ethical approval was obtained from the Health Research Ethics Board, University of Alberta.

CHAPTER IV

Findings

The purpose of this research was to investigate whether a brief educational intervention in a pre admission clinic had a significant impact on the completion rate of ADs prior to surgery. Specific questions posed included: 1) are the experimental and the control groups comparable; 2) what was the written AD rate that was effected after the PAC intervention; and was this affected by pre knowledge; 3) what was the verbal AD rate that evolved post education; 3) what did people think of the PAC education and, 5) what did they think about the actual AD document. The findings will be presented in relation to each of these questions.

Question #1: Are the experimental and control group comparable?

There was no substantial difference between the groups on age, gender, religion, spirituality and severity of surgery (See Table I). However, there were differences in marital status and number of health concerns. In the experimental group 92% were married as compared to 76% in the control group. As well, 4% were single/separated/divorced in the experimental group, whereas there were 18% in this group in the control. There were greater numbers of persons in the experimental group (70%) with ongoing health concerns (e.g. chronic obstructive pulmonary disease) than in the control group (53%). It is noted however that the severity of the surgery was comparable for the two groups. These were compared by classifying the surgeries as minor (such as the insertion of a moncref catheter under local anaesthetic), medium (such as a gall bladder removal when not done via 'lap-chole'), major (such as a triple

coronary artery bypass graft) and severe (such as a palliative, 'Whipple' procedure for wide spread cancer).

Table I:

The Comparability of the Experimental and Control Groups

Characteristics		Experimental	Control
Age		x = 61, S.D.16	x = 52.9, S.D.17, p. 0.01
Gender: male		60.4%	62%
female		39.6%	38%; p = 0.00001
Religion		Judaeo-Christian	Judaeo-Christian
Spiritual		93%	85%
Pre-PAC AD		13.3%	10.2%
Severity of surgery:	small	21.3%	16.7%
	medium	34%	38.1%
	large	38.3%	35.7%
	severe	6.4%	9.5%
Marital status	married	92%	76%
	divorced/single	8%	24%
Chronic Health Concerns.		70.6%	52.6%

Question #2: Did the AD education in the PAC setting effect a significantly different written rate of ADs in the experimental group than the control group.

There was a statistically significant difference with 99% confidence between the experimental group and the control group with respect to the post written rate of ADs: 20.5% of the people who experienced the AD education wrote an AD before their surgery; as compared to 0% in the control group.

Question 2A) Was the written rate affected by pre-knowledge.

In PAC, the experimental group were asked to rank their knowledge of ADs on a scale of 1 to 4, with 1 being no knowledge and 4 a great deal of knowledge. Of this sample, 27% had not heard of ADs while 20% of the respondents felt well informed on the topic. Of the 20.5% who wrote the AD, 50% had no or minimal pre-knowledge and 50% had considerable information in advance of the intervention.

Question #3: What is the Verbal AD rate, in the experimental group, after the PAC intervention as compared to the control group.

The verbal AD rate, post PAC intervention is statistically significant at the 99% confidence interval. 77% of persons in the experimental group, following the PAC intervention, discussed their AD wishes with their 'significant other' before surgery, while 0% of the control group dictated a verbal AD during this window of time.

Question 3A: With whom did the subjects discuss their ADs?

On the whole, when people gave a verbal AD, they gave it to their families. Subjects talked to their spouses, daughters, sons, or siblings. One individual discussed the matter with his nurse.

Question #4: Did the participants think that PAC was a good time to hear about ADs. Were they positive or negative about their experience of the 'education'.

76% of those asked were in favour of the PAC time frame. Three out of every four people who experienced the AD education thought that it was a good time to hear about ADs. 24% people thought that the PAC time frame was poor. 13 subjects were excluded because they were ambivalent (N = 3) or they didn't answer the question (N = 10) because the interview had to be terminated due to post-operative fatigue or illness, or changed the subject back to another aspect.

The qualitative data support these findings. Most people thought that PAC was a good time to hear about ADs. One person noted "it was a good thing. I didn't know that there was such a thing"; others recognized that although it may be frightening, it was a needed discussion; "face it, it is not a nice subject, but we've got to talk about it. PAC is a good time. It would have frightened me anyway (you fear that you will end up dead or incapacitated) it is something you have to face". Another commented, "(you) need to be aware of it. (It's) too costly to do afterwards (ie. get guardianship)".

People reported mixed feeling about whether or not the experience was frightening and stressful. Some said that it was too stressful a time: "scary". Two comments reflect this concern; "like an ad for a funeral home"; "it is not a good time. It is a bad time. ...need to think positively.....didn't want to think negatively. You have to have hope". In contrast, others said, "it didn't scare me. I already knew the dangers"; "(I) liked it...people need more teaching"; "If you are very sick, PAC is a good place: you are already thinking about this: the (surgery) consent talks about this"; "You have already had 'what if' questions".

Although, not everyone was convinced that PAC was the best time frame, all people concurred that a PAC time frame was better than admission. "They should give it to you in PAC. That is when you have the time. On admission, you don't have time to think about it": "I think pre-admission is better than admission. When you are thinking about surgery, it is as scary as it can get. But at least you have time to think"; "Admission is a very bad time".

People were divided as to whether the doctor's office was a better time. Some made comments such as "In a doctors visit, the person wouldn't think about it as strongly as they should. It does cause an extra anxiety in PAC. What other options are there?". Others disagreed and thought that "a better time would be post-op or at the doctor's office"; "(it) should be done before PAC"; "a health clinic or doctor's office would be better"; hospitals should be the last resort". Others thought the lawyers office would be the best, or that the "AD should come with the health premium statement".

Most people found that the AD intervention breaks up the time in PAC. "(It) breaks up the monotony"; "there is alot of waiting time in PAC"... "lots of waiting"; "(it) gives you something to do"; "PAC is a good time because there is enough time".

In general, most people gave a qualified endorsement; they said that it was okay for them but not for everyone; that it "depends upon the individual"; "it didn't scare me: some people would find it a bit much"; that they "liked it. It was a good idea, (but) it might frighten some people". "What has got to be done, has got to be done. It didn't bother me. It is a good idea but everyone is different". "It was a good time for me but if I had been going for a more frightening surgery it might have been different". It was "kind of stressful but then I made up my mind I don't want life support, just pain killer".

Due to the ambivalence that the patients felt, they made some recommendations for the procedure. One suggested that it is "different for each person. A pamphlet could be given, then the patient can approach the nurse if they want". Patients recommended that we "ask the person first before approaching them".

Question #5: What was the participant reaction to the Emanuel & Emanuel AD tool.

Fifty-nine percent (13/22) of the participants said that the AD was 'hard to understand'. Eight people (35%) specifically stated that it was difficult to grasp, three participants, 14%, stated that they did not read it and yet were interested enough to give their significant other a verbal AD. One person was illiterate, and one read Spanish only, thus the AD was inaccessible. Two people would not respond to this question and only addressed the second issue and thus 18/25 people found the tool too complex. Twenty-five people in this study were not asked about the tool due to health constraints at the time of the interview. This included severe pain, respiratory distress and fatigue. Often the researchers were asked to leave by the nurses or the patients, in one incident the researcher had to assist the patient with a severe asthma attack.

In summary, the control and the experimental groups formed comparable cohorts that demonstrated that education of the public with respect to ADs is both necessary and desirable. Overwhelmingly people thought that the PAC clinic was a good setting for learning about ADs. Further, most people appreciated the PAC education and went on to discuss their end of life choices with their families after PAC. However, most people did not write an AD and most people did not understand the document given to them.

CHAPTER V

Discussion

The conscientious bioethical health care person attempts to inform, educate, and empower persons to a position of autonomy over end of life decisions. With the understanding that most people do not wish to live life in the persistent vegetative state, this trial attempted to see if a PAC setting was an effective venue for AD education. To measure the effect of the intervention several outcome measures were used. These included: the writing of a personal directive, a verbal advance directive to a significant other, and the degree or level of patient satisfaction with the education.

Written Advance Directives

The main purpose of the study was to see if information given in PAC would lead to the completion of an AD prior to surgery. Although the written rate of 20% is statistically significant, it is not remarkable when compared with other studies outlined in the AD education literature. Three levels of intervention are outlined in the literature: a minimal intervention, a simple education and a complex intervention. The minimal interventions, like the distribution of a pamphlet usually achieve a 5 to 15% written rate outcome (Sachs, Stocking & Miles, 1992). The simple intervention, which combines pamphlets and a 'short' face to face interaction with explanation, ordinarily generate a 15 to 25% written AD rate (Hare & Nelson, 1991; High, 1993; Richter et al., 1995). Intensive interventions like that of Molloy, (1991) and Godkin and Toth (1996), where the professional spends 60 to 90 minutes with each person spread over two or more visits, typically achieve outstanding results such as a 50 to 80% completion rate. Thus, the achievement of a 20% completion rate with a simple intervention is comparable.

One reason this trial was undertaken in the first place, however, was to see if the 36% completion rate achieved by the Cugliari, Miller and Sobal's (1995) simple intervention, could be reproduced. As noted, Cugliari et al. (1995) provided a similar education to persons in 2 different PAC clinics and assessed the completion rate. Their rate was not reproduced in this study.

There are three obvious differences between the two studies: 1) in this study the control and experimental group were randomly drawn from one population, 2) this trial used a complex tool as opposed to Cugliari et al. (1995) who used the New York, Health Care Proxy document, which is a simple document and 3) this experiment took place in Canada and further, in Alberta, where advance directives had only just become law. While it is impossible to determine if the experimental populations were different in their desire to write ADs, it is clear that the tool did have some effect. As will be discussed later, many people in this trial stated that the Emanuel and Emanuel, Medical Directive (1995) was too complex and hard to understand. Thus writing this document was daunting in comparison to the more simple New York document used in the Cugliari et al. (1995) trial. The third explanation for the decreased written rate is the country and the province. Canada is well behind the United States in embracing and legalizing the AD document. Further, in the province Alberta advance directives (called Personal Directives) were legalized only in the winter of 1997. This is seven years behind the United States. Thus it is possible that with the American intervention participants in the study were more familiar with ADs and therefore more ready and willing to write these documents than their Canadian cohorts. It is of note that 27% (n=13/50) of this experimental group had never heard of ADs, living wills or personal

directives; 28% (n=14/50) had heard of the term but had no inclination as to its meaning. Thus 55% of the experimental group had no previous understanding of the AD phenomenon.

Verbal Advance Directives

In this trial, it is interesting to contemplate why, people liked talking about ADs in the PAC setting and overwhelmingly discussed and gave spoken ADs to family members, but mostly, did not write the documents. One is left with the situation identified by Emanuel, L. (1993) that people like talking about ADs but they do not like to write them.

The verbal rate, the rate at which participants in the study, post education, went home and discussed advance directives and their specific wishes with a family member, is remarkable. 77% went home and talked to either their spouse, 'family', son, daughter or sister about their end of life wishes. Three out of four persons gave verbal ADs to their family.

This has great significance as many people feel that this is the outcome of greatest importance. The autonomy of the dying person is maintained by the family as they advocate for the incompetent loved one. Furthermore, if the family is united by the dying person's directives, their one voice is extremely morally persuasive to most physicians (Dossetor, J.B., personal communication, 1997) and would probably be honoured if the incompetent person's situation is hopeless. As well, the Albert Personal Directives Act would support the family as a default entity for a written AD: in the absence of a formal document, the legal system does defer to the next of kin. The high verbal rate of ADs is also important because it enhances the relational ethics (of the

situation); the AD decision and discussion unfold with in the milieu of the family; 'the loved ones' are made part of the will, the dying and the dying process, thus enhancing relationships (Singer, 1995).

Although it is significant that 77% of the trial gave a verbal AD, it is difficult to assess how this rate compares with other educational interventions. There is little documentation about this event as very few studies have measured this outcome. There is one study by Jones (1998) which does measure this outcome criteria and has a verbal outcome of 73% for an intensive intervention and 57% for a minimal, pamphlet-only group. However, these data are not directly comparable to this trial since the subjects were recruited when they asked for information on ADs.

More research is needed to determine if using subjects who were recruited because they were going to have surgery is significant. Is this pre-surgery time frame a teachable moment? Due to its place in time, just before the major event of surgery does the PAC experience promote interest and impetus for action with respect to ADs. Does, as Reilly, Magnussen, Ross, Papa, and Wagner (1994, p. 2299) state, "hospitalization present unrealized opportunity for physician and patients to initiate these discussions". The Written AD rate does not suggest that the PAC 'time' is extraordinary. However, it may be that this timing is exceedingly important for people to talk to their families about their wishes surrounding advance directives.

It is known that people talk about ADs with greater ease than writing them. Emanuel, L. (1993, p. 12) states "there is less enthusiasm for writing instructions down than for talking about preferences and designating a proxy, which may reflect the inhibitions that many people feel about using legal documents or writing things down'.

Thus, it is acknowledged that a verbal AD will be higher than a written AD. However, this does not diminish the importance of this phenomena.

Of those surveyed, 96% (n = 28) stated that they discussed their end of life decisions with a family member that is, either their spouse, daughter, son or sister. Patients choose overwhelmingly to talk about ADs with their families, not their lawyers or health care providers. With increasing urbanization, health care is increasingly fragmented and the life long relationship with one's doctor is a thing of the past. Currently, patients see too many different specialists, nurse practitioners and other members of the health team to form strong bonds with any individual. Further, even if a person was to document an AD on a General Practitioner's chart, this would not be helpful in an emergent, hospital scenario. Often the GP is not made aware of the patient's situation until days after any event, and then it is by mail. Thus, the family, as the repository of the knowledge of AD wishes, is the most expedient venue.

Patient Satisfaction

Patient satisfaction is one of the outcome measures of AD education that has been valued and studied (Singer, personal communication , March 21, 1995). Overwhelmingly, people like receiving information about ADs (Singer) in doctors offices (Johnston, Pfeifer and McNutt, 1995), in long term care settings (Molloy, 1993), and other non-acute situations. However, as Emanuel (1993) and participants in this study suggest, people do not like receiving the information upon 'admission' to the Emergency department or on the day of surgery, as is common practice in Alberta, other Canadian provinces and in the United States. Because there are basically two ways in which to enter a hospital; emergent or surgical, the search to circumvent the admission

setting for ADs is paramount[1]. Thus, a measure of patient satisfaction in a PAC setting is of great interest as it has the potential to move forward in time the AD education from admission to pre-admission. The question being, if a pre-illness setting in the doctor's office is satisfactory but ineffective and the acute time of admission is both unsatisfactory and ineffective, what is the response to AD education in the PAC clinic with regard to both satisfaction and effect?

76% of the experimental group stated that they thought that receiving the Personal Directives information in PAC was a good idea. This number is substantiated by the qualitative data that were collected post operatively. In general, patients' stated that the PAC intervention was a positive one. They said that people need, like, and appreciate the teaching because it is important. Many people stated as well that it was not frightening to learn about ADs within the PAC context. They already knew about the complications of surgery, as they had just reviewed many possible scenarios with their surgical team when they signed the consent, and they had already been thinking about these negative possibilities. Thus, to have these complications re-discussed with a view to talking control of them was positive. Further to this, those who were very ill and were facing potentially morbid situations were aware of the various scenarios which might play out.

Although 76% stated that they felt positive about the PAC experience, there were those who felt negative about the intervention. They stated they did not like to

1. It is possible to enter the hospital system through direct admission to a medical floor, usually for extensive testing. However, the predominant mode of admission to medicine is via the emergency department and to the surgical units via PAC and then surgery

think about the morbid scenarios which might evolve, and found thinking about these stressful and frightening. These participants felt that discussing disturbing outcomes and end of life decisions made them think negatively when they should be thinking positively. It may be that these individuals represent 'blunters' as described by Miller (1987) who chose to avoid situations in which they can not have control.

Although, the PAC education was stressful to some of the patients, all participants stated that the PAC time frame was certainly better than the admission period which is the current, compulsory venue for ADs in Alberta and in the United States. All surveyed persons, when asked to choose between PAC or admission chose pre admission. This confirms what many scholars and researchers have been saying. Johnston, Pfeifer and McNutt (1995) found that 91% surveyed believed that ADs should be 'done' before one became ill, 84% wanted discussion to occur while the person was still healthy. Emanuel, L (1993) stated that the outpatient setting is best and noted "few would have proposed the time of admission and a clerk of the health care facility for this job" (1003, p. 12). Haisfield, McGuire, Krumm, Shore, Zabora and Rubin (1994) as well find that an early time frame is best so that there is time to contemplate the matter.

Many people felt that PAC was an excellent venue in which to hear about ADs because there was a lot of waiting time in PAC. This was particularly true for those undergoing complex surgery or who had several disease conditions where the wait was even longer as they needed to undergo many interviews and tests. Therefore, these people welcomed the interruption of the boredom.

It is recognized that participants could have stated that they 'felt positive' about PAC because they were worried about either 'hurting' the researchers feelings or 'displeasing' the researcher . This 'positive self-presentation' threat to internal validity has its greatest potential to contaminate here. This is somewhat controlled however by the researchers insistence of the importance of the data being collected and thus the responsibility of the subject to accurately reflect their experience.

In general, participants thought that the PAC education was a 'good' thing. It was important, not usually frightening (because patients heard about all the surgical complications from their surgical team), timely when compared to an admission time frame, and for those who spent many hours in PAC, it was a welcome distraction.

The participant reaction to 'The Medical Directive, the Advance Directive Tool.

The majority of people surveyed said that they found the AD too complicated (72%) and too hard to understand (60%). The Medical Directive (Emanuel and Emanuel , 1989) is 8 pages long and does require the person to have an understanding of "cardiopulmonary resuscitation..., mechanical breathing..., dialysis..., and artificial nutrition and hydration" (p. 2). Further, it requires persons to think about five morbid situations. This could be daunting for someone not familiar with medical and nursing terminology.

Health care professionals in contrast were excited about this Medical Directive. Through word of mouth, it became known that this research team carried an excellent directive and many doctors and nurses requested copies of the AD for their own personal use. Thus this research points toward the fact that this AD is excellent for

those who are extremely knowledgeable of health care procedures and language and not so helpful to those with less interest or knowledge in health care specifics.

The debate about the long , detailed AD vs. the short, simple directive is on going. Lay people prefer a "short and simple format with reading material at a level appropriate for the patient" (Haisfield et al, 1994, p. 1179). However, when doctors have to put these ADs into practice they have found that the short and simple directives are too vague to be implementable. The long and detailed ADs are much more useful at the time of incompetence. Singer, in his work with disease specific directives, found that these are very favourably received. However, the generic situation which requires an all purpose document leaves one with the conundrum of short and simple or long and detailed. There is no obvious solution to this dilemma except to say that for those who can write a detailed AD they should be encouraged to do so. However, for those who find the lengthy and specific AD too daunting, a short and simple document should be provided to them. A vague AD with nothing but guidelines (i.e., no heroics) is better than no AD, especially with a proxy named who will be able to assist in the interpretation and details of the end of life situation. It may be that choice of documents is required to promote the written AD. Thus, when the educator is presenting ADs, several different types should be put forward.

This being said, a very possible explanation for the expressed ambivalence toward The Medical Directive is the fact that participants didn't execute it. Therefore, the document provides a very plausible excuse for the lack of written directives. Did people not execute the directive because they couldn't 'put pen to paper' or did they not

put pen to paper because of the tool. The literature would say that the writing is the cause. The participants stated that the tool was a problem.

Is PAC a teachable moment? Prochaska revisited

Is PAC a vehicle for AD change? Prochaska's 'pre contemplation' stage clearly takes place in PAC. The patient in PAC is a captive audience because there is nowhere for them to go and the topic is of imminent interest to them. 'Contemplation' takes place after the intervention. The person reflects upon the discussion and the brochure as they wait in PAC, return to their home, and prepare for their up and coming surgery. Contemplation is evident as 76% persons went on to 'preparation' through discussing ADs with their families. Prochaska's 'action' phase is only reflected by 20% who wrote the document. 'Maintenance' is achieved by the patient asking to have the document on their chart or the ward clerks questions pertaining to their ADs. PAC is a teachable moment and the Prochaska model assists in an explanation of the process of change.

Limitations of the study

Several problems arose during the implementation of this study. Issues related to the selection of subjects and data collection procedures posed serious threats to the internal and external validity of the study. Consequently, the research findings must be considered tentative given the problems encountered.

The first threat to internal validity was the problem of maturation (a broad cognitive change). Specifically, the subjects in this study were tired and fatigued due to the combined effects of being part of this study and their illness.

The second problem was concerned with the inability to collect complete data from both the experimental and control subjects. Obtaining complete data

preoperatively with the experimental group was impeded by the requirements of obtaining written formal consent from all participants. Patients generally indicated that they found the consent process very stressful. Patients stated that they did not mind answering the study questions but questioned whether or not it was necessary to formally sign the consent to participate in the study. Therefore the process of consent (ie. the length of time required to get patient consent) and the time required to provide the AD intervention often led to decreased time to obtain the required study information, and the patient demographic information that was of interest.

Post-operatively, data collection from both groups was daunted by the fact that the study subjects were sick patients. They often had little or no energy to spare. The experimental group was more affected by this than the control group. If the control subject was very sick, they refused to participate, or were unable to participate and then were excluded by the researcher. For example, one patient was willing to participate but she was short of breath and on a ventilator. It would have been inappropriate to continue. Patients who were repeatedly ill upon solicitation were dropped from the study. This was not the case with experimental patients. In the event that they were very ill, one shortened the question period and asked the outcome measure questions only, thus tiring them minimally. One did not have this option with the control group as there was the very time consuming consent to fill out. In addition, the decision to shorten the questionnaire, or asking only outcome questions resulted in missing the data which may have affected the results generated by this study.

This drop out rate or attrition resulted in a selection bias and would therefore affect the comparison in the two groups. Very few people refused to enter the

experimental group; they were basically healthy people with nothing else to do but wait. The refusal rate in the control group was high; they were recovering from surgery, trying to get better so that they could go home. For the control often 5 people would be approached before one would agree to be a control subject; these were sick people; they were recovering from surgery; these people refused because they did not feel well enough to participate. There was a second type of 'drop out' factor in the experimental group that was not present in the control group. The experimental subjects were approached twice: pre -op and post-op. If they were competent during PAC, they were solicited and if they were permanently incompetent post-op they were deleted. The sample size was increased to control for potential experimental 'drop out'; however, one cannot exclude the effects of selection bias on the validity of the study conclusions.

Due to sampling problems due to the revised protocol put in place by the ethics committee, there were differences in the number of minor surgeries in the two groups (16.7% control; 21.3 experimental). Potential subjects in the control group who had minor surgeries were frequently lost to enrolment in the trial than those who had more major surgeries. Even though the researchers were aware of the short length of their stay, patients were often discharged the moment that they were competent. Patients in the experimental group with minor surgeries could be followed up at home by telephone. In all probability it is not likely that this affected the AD written completion rate: 20.5 vs. 0%. Despite these confounders, data collected about the two groups show that the groups were quite similar.

In conclusion, the limitations of the study, discussed previously have posed threats to the internal and the external validity of the study conclusion, the difference in

completion rates between the experimental group (20.5%) and the control group (0%) must be considered tentative.

General Recommendations for Nursing Practice

It is recommended that Nursing introduce AD education in all PAC settings. To do so represents an unparalleled opportunity. The nurse is a natural patient advocate (Henderson, 1995) and patients enjoy talking with the nurse about ADs (Haisfield et al., 1994). A PAC clinic is run by nurses and advance directives could quite readily become part of pre operative teaching for any patient who is to undergo general anaesthetic and invasive procedures. Specific recommendations for PAC administrators and PAC nurses are threefold. The first recommendation is the inclusion of a card with the other forms that need to be filled out when the patient arrives at PAC. This card would ask the patient if they would like to receive information about ADs during their visit. Thus the person can decide if they want to raise this topic during their time in PAC. The second recommendation would give the patient further control by asking them, within the preoperative teaching session if they would like to have an explanation or merely to receive written information to take home. Again this responds to the delicacy of the topic and the patients' ability to focus on it. The third recommendation is to offer a choice of directives to those interested; the long and implementable AD, the short and easily executed document, or perhaps a disease specific one. The patient should also be informed that the long one is easier for the doctors to follow with any precision and if they would like to execute this one, further help can be made available..

Nurses need to become more knowledgeable about ADs. By teaching nurses and in turn having them become more responsible for the teaching of patients, the

knowledge of other health care professionals will also increase. As Singer and Segal (1992) point out that by teaching our patients we will end up teaching other health care professionals because the need to know will be patient driven; consumers will demand that their health care providers be informed.

Recommendations for Further Research

More further research about advance directives and education needs to be conducted. We are only at the beginning of our understanding of patient AD education and the variables that impact on people's decisions to write an AD.

Studies indicate that patients like education done in the doctor's office. A comparison between the doctor's office and PAC, using an educational intervention similar to that done in this trial is warranted. Patients' indicate that AD's should be addressed early in their health care experience. The doctor's office would be earlier, yet PAC offers a potential impetus for action that is not present at this earlier time.

Research must also address the concept of the teachable moment with respect to AD education. End of life decisions can be avoided endlessly. As health care advocates we must be sure that this is what they want. We must give them the information that they need in order that they may be able to express their autonomy and their authentic expression of self with respect to their end of life decisions.

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APPENDIX I

EXACT NATURE OF THE INTERVENTION TO THE EXPERIMENTAL GROUP IN PAC.

Format for the educational interaction for the experimental group:

Hello, my name is Madeline Jones. I am a nurse. I am also a student at the University of Alberta, who is doing their Masters of Nursing. I am doing a research study to gather information about people's knowledge of Personal Directives; you may know these by the name of Living Wills or Advance Directives? Do you have a few minutes to talk to me?

IF YES?

Before we talk, it is important that you sign an informed consent which A) outlines the purpose of the study that I have just mentioned, B) says that you do not have to talk to me if you do not want to and C) that no one will know that you are taking part in this study unless you tell them; your name will never be used anywhere in the report of my study.

CONSENT REVIEWED & SIGNED

Have you heard of Personal Directives?_____ Y / N.

Barely A Little/ Some A lot

Increasingly, it is felt by health care professionals that everyone should have a Personal Directive. These are documents that give the individual health care choices and allow the patient to maintain more control of their health care. They tell the doctors and

the nurses what your wishes are in the event that you are unconscious, or are not mentally able at the time when something major happens to you - such as your heart stops beating suddenly. Written directives also can help families make decisions for you if ever you could not.

I would like to give you a copy of a legal Personal Directive that you could look at when you have time. It is a real Directive and you can fill it out if you want it. If you wish you may share this with your family. Doctors honour both the directives and your family's stated wishes for you.

Do you have any questions?... Let me leave you my card in the event that you do have a question that you would like to ask me (High, 1993).

I will touch base with you after your surgery to see if the material I gave you was helpful. Thank you for speaking with me.

Appendix II

DATA COLLECTION FROM THE EXPERIMENTAL GROUP ON ADMISSION TO THE HOSPITAL, JUST PRIOR TO DISCHARGE

Hello, it's Madeline Jones, the Masters Student, who talked with you before your surgery and gave you information about personal directives or living wills. How are you doing? Do you have a moment to talk? I would like to ask you a few questions about the pamphlet and when you got it?

Question #1 What did you think about being given that pamphlet in the pre-admission clinic. Did you think that that was a good time to give you that information?

Y / N

If no: What would (in your opinion) be a better time

_____

Thank you, that is very interesting.

Question #2 Because we want to evaluate the information that we gave you, may I ask you if the pamphlet that I gave you made sense to you:

Was it hard to understand ? **Y / N**

Was it too complex ? **Y / N**

If no? How could the pamphlet have been more helpful to you? _____

Question #3

May I ask you, did you complete a directive? **Y / N**

If yes. What did you do with it?

_____

Did you speak to anyone about it? **Y / N**

If yes, Who did you speak to?

_____

If No. Would you mind telling me why?

_____

Probe: Some people don't want to fill them out (or talk about it) because it sort of seems like one is tempting fate.... What do you think...." ?

Probe: Some people feel that they just don't have enough information to formally write it. What additional information would you need?

Appendix III
DATA COLLECTION FROM THE CONTROL GROUP, AFTER HOSPITALIZATION JUST PRIOR TO DISCHARGE

Hello, my name is Madeline Jones. I am a nurse. I am also a student at the University of Alberta, who is doing their Masters of Nursing. I am doing a research study to gather information about people's knowledge of Personal Directives; you may know these by the name of Living Wills or Advance Directives? Do you have a few minutes to talk to me?

IF YES?

Before we talk, it is important that you sign an informed consent which A) outlines the purpose of the study that I have just mentioned, B) says that you do not have to talk to me if you do not want to and C) that no one will know that you are taking part in this study unless you tell them; your name will never be used anywhere in the report of my study.

CONSENT REVIEWED & SIGNED

Increasingly, it is felt by health care professionals that everyone should have a Personal Directive. These are documents that give the individual health care choices and allow the patient to maintain more control of their health care. They tell the doctors and the nurses what your wishes are in the event that you are unconscious, or are not mentally able at the time when something major happens to you - such as your heart stops beating suddenly.

I am randomly talking to people who have gone for all kinds of surgery and trying to find out how many people actually have completed one.

What I am interested to know, if you don't mind sharing this with me is:

Question #3:

If you have completed a directive? **Y / N**

If yes. What did you do with it?

_____

May I ask you, did you speak to anyone about it? **Y / N**

If yes. Who did you speak to?

_____

If No. Would you mind telling me why?

_____

Probe: Some people don't want to fill them out (or talk about it) because it sort of seems like one is tempting fate..... What do you think...."?

Probe: Some people feel that they just don't have enough information to formally write it.

CLOSING: I can give you a copy of a legal Personal Directive that you can look at when you have time. It is a real Directive and you can fill it out if you want it. If you wish you may share this with your family. Would you like some written information.? If yes: Provide. Do you have any questions?... Let me leave you my card in the event that you do have a question that you would like to ask me (High, 1993).

Appendix IV

Data Sheet: DEMOGRAPHIC INFORMATION

Question #4: I am also trying to get a picture of people who complete and don't complete ADS so we can develop appropriate information for all people about ADs. May I ask you about your age, religion and occupation & other questions such as the ones listed on this page (Show patient the page) or (if you do not mind sharing this information with me) would it be easier for you if I got this information from your chart. If there are any questions that you would prefer not to share please tell me and I will omit those.

1) Age_____

2) sex: Male---------Female

3) marital status_____

4) chronic illnesses:_____

5) occupation_____

6) religion_____

7) ethnic origins_____

8) education_____

9) Diagnosis_____

10) Surgery_____

Consent to access chart: I give _____ permission to look at my chart for the purposes of getting the above information.

_____

name of patient/signature

Appendix V

DETERMINATION OF THE SAMPLE SIZE THAT IS REQUIRED

Event rate in the control group, (Cugliari et al., 1995) = 4%

Event rate in the experimental group, (Ibid.) = 40%

$P_c = 0.04$

$P_1 = 0.40$

$P = (0.4 + .04)/2 = .44/2 = .22$

Study = one tailed with a = 0.05 and power = 90%

$$\frac{2N = 2\{Z_A /2P (1 - P) + Z_B /P_C (1 - P_C) + P_1 (1 - P_1)\}^2}{(P_C - P_1)^2}$$

Z_A @ 0.05 LOS, one sided test = 1.645
$Z_B = 1 - B$ @ power = 0.90 = 1.282
Friedman, Furberg & DeMets, 1985, p. 89)

$$\frac{2N = 2\{1.645 / 2 (.22)(.78) + 1.282 / (0.04)(0.96) + (.4)(.6)\}^2}{(0.04 - 0.4)^2}$$

$$2N = \frac{2\{0.963694858 + 0.676429658\}^2}{0.1296}$$

$$2N = \frac{2\{2.690008429\}}{0.1296}$$

$$2N = 41.51247575$$

$$N = 21 \text{ people}$$